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From: "sarah boyce" <saraheboyce@hotmail.com>
To: <wvogl@samhsa.gov>
Date: 7/11/2004 9:32 AM
Subject: Revised Mandatory Guidelines FR DOCKET 04-7984

Dear SAMHSA Administrator:

I am writing as a 34 year old woman with paruresis, or "shy bladder," to express my concerns about the proposed new regulations regarding urine samples. I work full time in research, i'm married, and I don't use drugs. Please understand that paruresis, while it sounds like a strange affliction (even to us sufferers), is very real. We would all be more than happy to be able to urinate on demand, or even in normal everyday public situations, but often cannot. Degrees of paruresis vary by individual. Mine was more severe as a teenager and improved slightly in college, but I still remember frequently finding a quiet bathroom where no one would come knocking on the door. I also remember going to the health center in college because I couldn't urinate, and tried to seek medical attention. I was told they did not have catheters, and was told to take a bath. (not an option at college, nor would it have helped).

From the age of 12 to 27 I thought I was the only person in the world with this problem. If I had to face a drug test during that time, I don't know what I would have done or said. I certainly did not know the term "paruresis." Drug testers should be trained to be aware of the affliction.

At age 27 I discovered the International Paruresis Association (IPA) and their techniques have helped me learn to manage my paruresis in a much better manner. But different people have different levels of success, and although i've improved, it's often still a concern in public situations, especially if other people are waiting for me.

With other techniques available for drug-testing, please consider incorporating them into the regulations. No true paruretic will resist another option for drug testing. They will be grateful.

If a paruretic cannot produce a sample, it is because they are truly unable to do so. To fire a paruretic due to "refusal" to produce is simply wrong and unjust. Forcing someone with "shy bladder" to stay at the testing site for 3 hours does not help. Often as time goes on it becomes more difficult for the person to produce a sample. And as the bladder becomes more full, the pain is substantial.

I have a self-cath kit, and while I have only had to use it once, I always have it when I travel just in case I find myself in a situation where I cannot urinate normally. It seems to me that allowing paruretics to provide urine by self-catheterization would be a reasonable provision to add.

Please take seriously the comments you receive from paruretics on this issue. We are not trying to get out of the testing, we are simply asking that alternative methods be made available. Drug testing is an important, and unfortunately necessary part of today's world. But do not punish those who are innocent of drug use, and simply guilty of a medical disorder. Thank you very much, and I look forward to hearing the outcome of the comment period.

Sincerely,

Sarah Boyce